2019 Submission - Royal Commission into Victoria's Mental Health System

Organisation Name
N/A

Name
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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
N/A

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
N/A

What is already working well and what can be done better to prevent suicide?
N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.
N/A

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
N/A

What are the needs of family members and carers and what can be done better to support them?
N/A

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
N/A

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?
N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
N/A

What can be done now to prepare for changes to Victorias mental health system and

support improvements to last?
N/A

Is there anything else you would like to share with the Royal Commission?
N/A

#9 5/7/19

PREFACE:

1. for convenience, unless otherwise specified, ‘staff’ will include any medic, nurse, allied health, social worker, etc.
2. unless specifically designated, ‘you’, ‘I’, ‘us’, ‘the people’, ‘patient’, etc., refer to me or other non-staff people.
3. ABI = acquired brain damage
4. a reference to ‘too many’ can mean as little as ‘one.’ The damage that one person can do can ripple out, so even one person erring, or one mistake, can be too many. A case on point is the 1990’s misreading of my MRI. Despite comment about brain damage on my discharge sheet from [redacted] Hospital, the MRI staff ‘read’ the ABI as ‘an arachnoid cyst,’ when there was extensive damage of the actual brain. For the better part of 12-15 years, I was treated like a slacker, and given no assistance, because I ‘officially’ had a cyst, not brain damage.
5. MHI = mental health issues

How do people access Victoria’s mental health services? I’m not sure. Like public ABI clinics, I have knocked on many doors that have remained closed. You need to know this service exists before you can access it.

The ‘catchment’ system is a nightmare barrier to receiving timely and appropriate assistance.

There needs to be better education/awareness of services among staff. Staff need to be trained and reminded to tell patients of support services, like Arbius, Brainlink, etc. I had an ABI for nearly 20 years before I stumbled onto a reference to Brainlink and found another ‘world.’ Access to that is still difficult, but at least now I know about them.

There is also the issue that some services and groups seem to be somewhat dysfunctional, with personality, cliques, ambition and all the usual ‘horrors’ of human interactions in group situations quite prevalent.

*What are the drivers behind some communities experiencing poorer mental health outcomes and what needs to be done to address it? This can tie in with ‘Navigation of the system/services’ and the above access issues.

There is too much reliance on online facilities, especially in rural/regional areas. In the area of Ballarat I was living in until recently, it was still dial-up. NBN is coming before broadband. There must be recognition that many people do not have in-home internet services. Public libraries are a common form of access, but are often too noisy, with other distractability issues, and some people are unable to properly read from screens. Screens also remain an issue for the literacy, hearing and vision impaired. Face to face is necessary. Shouldn’t all information be in formats, to ensure accessibility for all?

There is a need to streamline ALL phone services – from hospitals, to utility bills, local councils, banks, etc. Too often, one must endure several, or more, pushed buttons to try to talk to/ask a simple question of a human. Then there is the interminable ‘Your call is important to us, please hold the line.’ An article in The Senior magazine, 29/7/2019, about the Royal Commission into Aged Care Quality and Safety, sums this up. It cites a witness saying:

> 'It relies on people having the telephone, internet, being in a fixed address and speaking English and being cognitively intact and not too frail to have the energy to deal with the system.'

Such comment is pertinent to MHI, especially the last, about having 'the energy to deal with the system.'

Further to best practice treatment and care workers that are safe and person-centred, be very, very careful employing people - peer support workers and staff - whose main 'qualification' is 'lived experience.' From the few I've seen/met, at least half have unresolved personal issues, that quite obviously impact on their work.

Staff should be trained in empathetic and sympathetic personal relations. Three incidents, among a number of examples, are:

1. I was trying to explain past and present difficulties in relation to a question asked by a neuropsychiatrist, Dr [redacted]. He replied: 'What do you want me to do? Cry, or pat you on the back?'
2. when undergoing an internal examination by a male gynaecologist at [redacted] Health Services ([redacted]HS), I said that the procedure was hurting. His comment was: 'How would I know? I don't have a vagina.' The BHS response to this? The doctor was apparently 'counselled.'
3. a colon doctor at [redacted], was performing an external examination. I commented that the area was sore. He said, 'It doesn't hurt to look.' I didn't bother to report him.

Why bother reporting if standards are so fluid and won't be maintained anyway? The three scenarios compounded and exacerbated existing depressive and anxiety issues.

Ensure that people are treated with respect and consideration. I went to ask about a follow up appointment with neuropsychiatry at [redacted] Hospital, in late April, 2019. At time of writing (June-July, 2019), I am still waiting for the 'next day' phone call about the follow-up appointment.

Stop the bullying of patients, especially the ones who don't fit into 'conventional' boxes, or categories. Those with multi- or co-morbidities need proper (w)holistic assessment and treatment.

A common sense and (w)holistic approach is needed. I have an ABI, with no right front temporal lobe. This is apparently where most of the anti-depressant drugs work, yet staff still discuss these drugs as an option. As I am reluctant to take such medication for this reason, I apparently have a reputation as 'non-compliant.'

At one stage, there was a (mis)profiling me as obsessive-compulsive, because apparently injury to the right front temporal lobe can result in both epilepsy and such behaviour.

I tell staff I have aphasia. They nod, then continue blasting questions at me, never allowing time for me to process them, let alone organise myself for a reply. Too many presume to draw conclusions on the basis of scraps of information, then make pronouncements that reverberate through and down the 'system', usually impeding assistance to the person.

What happened to the duty of care?

There needs to be checks and balances on medical reporting and, per above, how to deal with errors, misperceptions and mistyped 'information.' Will this be exacerbated by the MyHealth record system, or will that be a way that errors are picked up and corrected, and staff encouraged to take more care when writing reports and file notes, rather than mistakes being left to reverberate through the system?

This is if staff bother to take, let alone write up file notes, etc. Dr [redacted], at [redacted] Health Services, 'confessed' after some 6 years of appointments that there had been no therapy in that time and seemed unable to recall what had been done. He apparently did not have any file notes to act as reminders, or records.

Many staff need reminding that they are not god(s). They are human and do need to take care. It's their responsibility and they must be held to it.

Too many staff have a 'don't know, don't care and won't take responsibility anyway' attitude. There's far too much condescension, latent contempt and paternalism in staff attitudes. A neuropsychologist at [redacted] wrote two very different reports on tests she gave me: one was sent to the GP/other doctors and one, with different wording, to me for my 'records.'

Too many staff have a tendency to martyrdom and drama-queendom, proclaiming they are there to 'help;, etc., when, too often, all they are facilitating is their job and learned helplessness and continued ignorance in the patient. What happened to the notion of loving-kindness as a basis for life and action?

The difference in treatment and attitude by staff to public patients, compared with private patients, verges on the catastrophic. Dr [redacted], neuropsychiatrist at [redacted], explained why he wouldn't refer me on: 'You won't pay for anything.' I have lost count of the number of times I have been told that I could not have a test, procedure, or treatment because I was 'not insured.'

Interviews need to be more responsive to the person/client. Even after I have told staff about aphasia, ABI and, problems with auditory memory, processing of information and short term memory, etc. most nod politely and carry on as before. When they say 'Now, as you said before…', most do not take kindly to me saying:' What did I say before?,' let alone when they refer to previous appointments, which could be 1 week to 1 year previous. When I ask a question, staff reply 'But, I've just told you about that… '

Although I have repeatedly requested appointment notes from staff, there is only one doctor, GP, Dr [redacted], who will write up appointment/ interview notes with any regularity and with some timeliness, so I do have a chance to read something and retain some memory of what had been said/discussed. More usually, if extremely lucky, I might receive a copy of the doctor's report some weeks/months later. Usually there is nothing.

* Box-ticking and the way staff profile you and your particular needs, needs to be addressed. Per the above examples, too many staff merely tick boxes, to process clients and cover bookkeeping/statistics. Staff need to be trained and have an administrative system that supports reminding them to do things they have said they would do. There is a necessity for more full-time positions, so there is a continuity of and access to staff.

If you don't fit staff perception of depression, you're shown the door – much of the time being considered a sham - and no one else will assist.

If you don't fit staff profile of depression, you don't have it. How then to account for the comedians, who deal with mental health issues by 'laughing', a number then suiciding? There's then fuss from 'professionals'/staff: 'Oh, they were always laughing and smiling. How should/could I know they were depressed?'

There MUST be recognition that some people deal with depression in different ways, rather than catastrophising everything and complaining and crying all the time.

It must be remembered that some people cannot cry and others have no more tears left to come out. Others are unable to express/release emotions in this way, so 'channel' these negative/depressed emotions through impulsive, or aggressive, behaviour, lack of self-care, impulsive purchases, risky behaviour, etc.

Even not using medical equipment, because 'I can't be bothered,' should act as a cry for help and a warning that all is not well and potential or current depression should be investigated.

For those with brain injuries, it is my submission that there is far too little professional acknowledgement and public knowledge and self-awareness of the three 'A's:

- amnesia (covering all aspects of memory);

- aphasia (not limited to stroke patients); and

-adynamia – this latter being one where the family, friends, colleagues, medics of the patient misperceive the person's inability to perform especially acts/functions, that they seem capable of, as 'lazy'. The person themselves may be unaware of this and self-perceive themselves as 'lazy,' thus exacerbating their MHI.

Fostering self-awareness should be mandatory, especially if one of the behaviours of concern as a result of the brain injury is denial of anything being wrong. It must become socially and professionally acceptable to say: 'I can't do this,' 'I find this all a bit much,' 'I'm not coping' etc. The person is not slacking, lazy, or throwing in the towel. We are making a statement of our reality and the rest of the world will just have to catch up.

*NEEDED: Tests of neuropsychological or neurocognitive function that are tested in 'real-life' conditions, not soundproofed bunkers and quiet rooms, with tests that include tests that test/assess ability to bring things together, etc. Current tests that I have had are far too linear and test long term memory, rather than current ability.

*Social and economic participation is a bit tricky, especially as the two are almost always conjoined like twins. There always seems to be the undercurrent of 'you're costing us money' and 'when will you pull your own weight?,' etc. It begs the question: can those with MHI only be part of society if we participate economically? Doesn't this speak volumes about the current state of 'society'? Does this state of society suggest that the late Maragret Thatcher's (in)famous statement that there is 'no society' is right? There's no society, just economic participation, or you can't participate in and belong to society, unless you participate economically? Some years ago, I attended a class reunion. I was asked what I did. When I said 'medically retired,' people's reaction was to sneer: 'Oh, you're not working,' cross their arms, turn their backs and walk away.

Re MHI/suicide, other people just do not want to get involved. eg: a man, a house husband, had a night off and went to his local pub. A mate came over and started lamenting about how his wife had left him and how he felt like dying. The first man's response? 'I didn't want to know. I was just down at the pub for a drink and a night off.'

A relative told me about a phone call they'd had from an old work mate. 'He sounded like such a misery that we didn't follow him up.' This comment knowing that, some decades ago, the man had lost a 10 year old daughter to cancer, separated from his wife and mother of their two children, and watched his remaining child spiral into drug use.

As noted in the above context about the disfunctionality of some support groups, 'society' is fraught with issues. There's snobbery, 'in'/'out' groups, cliques, economic and class standing and status, personality, social mores and actual law, politenesses, etc.,…then, there's issues associated with the stigma of MHI.

In Australia, it is still quite difficult to interact socially without alcohol. I recall from working in the area of workers compensation and TAC law. On the basis of medical reports in 1994, we would need to broach the issue of containing, reducing or cutting out alcohol intake with some clients because of their medication or injury (eg: ABI, etc.). This was quite difficult. Protestations that I, or other lawyers/professionals, were not wowsers, but workers who had been primed by doctors to reinforce the doctor's advice to the client about such things, often had to be very loud before the client would listen, let alone believe. The stigma of MHI and not having a 'social' drink of alcohol is a significant double whammy. In social settings, I am looked askance when I say I don't drink alcohol.

'Busy' is another socially acceptable state, with 'Are you keeping busy?' often used as a greeting and 'So, you're keeping busy,' a compliment. The perceived 'need' to be 'busy' can undermine mental health and exacerbate MHI. I have known people to ride buses 'to fill in the day' and 'keep busy.' What happened to [translate the following according to your religious or philosophical belief] 'Be still and know that I am God.'?

Sometimes, MHI can be perceived as 'going with the territory,' for some creative types, such as artists and musicians, or the occasional 'dotty' scientist, etc. The [old?] stereotypes of the anguished artist in the garret, the 'lost in sounds' muso and the white-coated, scatterbrained scientist who just loves his research cats, were staples for cartoons and comedy for a generation(s). Could the current generation draw on this to enhance their own MHI?

For other professions, or people/social groups, to even hint at the possession of MHI would be career, or social, suicide.

Be very careful with language. No longer are we 'people' 'patients' or 'clients,' we're now 'customers', or 'consumers'. That the NDIS is 'market-driven' speaks volumes. How do these subliminal messages reflect in people's mental health outcomes and issues, especially public patients?

A niche comment is about emergency accommodation. One I stayed in didn't have an induction pack, with all the rules and signage around the quarters in one place, so residents with literacy and ESL issues, currently so prevalent, take them to their case worker, or tutor/class, to learn what is expected of them. They remain ignorant, until a mistake is made. A young woman at emergency accommodation made the comment that 'Yeah, well, everything is old and grubby…' There was such low expectations of residents, that there was no recycling bin. Staff said 'Everything goes into the skip.'

How are even the most vulnerable and potentially incapable to be brought into society's fold when they constantly receive negative subliminal messages like this?

*What about real medical participation? Why wasn't this question specifically included in the terms of reference? Often, merely asking a question apparently brings into question the staff's capability, or credibility, so ego replies: there is little, or no, attempt to answer the question. There's all the 'right' words in hospital and clinic health charters about being involved in your treatment. The on-the-ground reality is that this is usually bunkum.

Needed and possible(?):

1. proper funding for broad research on meditation/mindfulness, etc. as a means of pain reduction and dealing with pain and breathing issues and mood, behaviour control, addiction withdrawal-alleviation, etc.;
2. more easily accessible natural areas. Have public transport signs at the entrance to all local, state and national parks, with a stop by request system. Could we dream big and have public transport buses do on request/demand detours into local, state, regional, national parks for passenger drop-offs, as occurs overseas. This would facilitate many people's access to nature and all its benefits;
3. a central place to report questionable behaviour that might be a conflict of interest, rather than illegal behaviour, or activity. eg: a woman in a church congregation sold aromatic oils to the most vulnerable. One man claims he did not know how to use them properly and this led to a psychotic episode;
4. Quiet corners/booths could be dotted around towns and cities. These would be totally soundproof booths, where a person could go, close the door and be enveloped in a comforting silence. I cannot be the only person to traverse both sides of the length of Bourke Street, looking for a quiet corner to recuperate in and, not being able to find one, have been left publically upset;
5. Phonelines are necessary and beneficial, but there appears a need to have face to face, anonymous drop-in booths. A young man was on a suburban train. He made seven phone calls saying 'goodbye' and 'I can't go on'. After some conversation, he commented about phone services: 'What's the point of talking to a telephone?';
6. take services and staff to the people/staff eg: VMIAC 'This is as far out as we come' [ie to Ballarat]. A Victorian Mental Health Foundation man claimed he could not travel to the further reaches of regional Victoria, as it would mean 2-3 days out of the office. Yet, workers travelling from those same regional towns, like Mildura, have to take a night bus, or an afternoon drive, down to Melbourne, stay overnight, attend the conference/training, etc., then travel back on that night's bus, or the next (third) day;
7. properly training and reinforcing this training about professional behaviour of staff eg: [redacted]), had a student with her on the first two occasions we met. Even after I commented, she did not ask my permission to have the student at the first interview. On the second occasion, she instead lectured me about how [redacted] is a teaching hospital. She said I should expect this situation on future occasions/contacts;
   She also said she would contact accommodation providers. Again, this was without seeking permission, let alone getting an authority to act. This is also after she and the student were brought to the room door of the accommodation house I was staying in, without giving prior notice.

*Family and carer support needs: it is time to relieve the onus on usually untrained family to take care of their mentally unwell 'child[ren]', or family member. In one case, an adult 'child' was still at home, even though there were apparently past issues with their father. After an altercation, the 'child' killed their father. The mother buried her husband, lost her 'child' to the Thomas Embling Hospital and jail for an unknown length of time, sold the family home because she couldn't bear the memory of what had happened there, and felt caught between her other children and this 'child', as the other children were also having trouble coming to terms with what had happened.

*Mental illness prevention:

1. has proper research been undertaken regarding the medicalization of 'normal' fluctuations of mood? ie: shouldn't a 10 year old child could be expected to be upset at the death of a friend from cancer, with the resultant depression and anxiety, etc? In the current medical climate, are drugs, not hugs, now being prescribed? Everyone is 'too busy' for anything else?
2. education about self-awareness and the manifestations of co-morbidities like ABI, etc and how these injuries may manifest themselves in behaviour and mood, etc. ensure and enhance self-awareness. Ensure that people are aware of the manifestations of their illness/condition: that a bump on the head may mean concussion, with, for example, a potential two week, or lifetime, manifestation of depression, etc.
3. education: public education, preferably advertisements that use 'serious' humour.
4. the public, government and society must address the need for spending public money on proper schemes, including proper supported accommodation, before mental health issues escalate into criminal behaviour and the 'need' for more jails.
5. included in this, should be the need for proper accommodation for the physically disabled, to address and maintain their mental health issues. In the 1980's, when my grandmother's dementia left her unable to care for her son, my second-oldest uncle, who had advanced fredricks ataxia, the only place in Victoria that could be found to offer him a bed, let alone the facilities for his condition and staff for 24 hour care, was Ouyen General Hospital. This was some years before the much-needed upgrade of the Sunraysia Highway;
6. further to entering the system and mental illness prevention, I was a little surprised that there seems to be no obvious separate designation for maternal and paternal health, particularly given some of the events over the past few years. Although though I am not a mother, so have no lived experience of it, I do have very vivid memories of a phone call from a friend, after his wife gave birth to their third child. He asked if I could keep in close contact with her and drop in from time to time, '…because I think she has the baby blues…' Shouldn't this sector have a specific reference within the terms of reference of this commission? Rest in peace Darcey Freeman and all the rest;
7. this is even more apt, as 2018 was the first reference in a conference linking brain injury to domestic violence – and resultant MHI from both - I had seen. It has taken this long and there still seems to be no proposal to have anyone subject to domestic violence – child or adult -automatically screened for brain injury?;
8. public education about invisible disabilities: that they are real , etc. How many with brain injury, or other invisible disabilities/illnesses, have received comments like: 'Well, you look alright to me. Why don't you get on with it?' implicit – intentional or not - in the statement is that the person with the invisible disability is a slacker. This does have mental health ramifications.

I would argue that the most fundamental causes of a lot of MHI have been written about for years. I do not have permission to quote in length from John Steinbeck's, *The Grapes of Wrath*, but refer to the chapter(s) noting that [my paraphrasing] '*... these things are results, not causes,...the causes lie deep and simply...*' In an unpublished letter to the editor of a newspaper, I wrote:

> This spectre of depression and anxiety is everywhere. People are reaching out for meaning and belonging and understanding: recognition of themselves as an entity and part of a whole.
> Older men are suiciding in ever increasing numbers?
> Of course: their world is gone. Their world: of a copy of *A Message to Garcia*, tucked away in their personal papers, or between the pages of an Army-issue bible; where their word and a handshake was a contract that would survive any possible challenge; talk was straight; there was mostly full-time work with a living wage; union membership for solidarity, friendship and extra insurance; job security for a job well done; free education and home ownership within a lifetime, not a debt beyond the grave. Companies don't pay tax like these people do.
> The older folks: their world, for which so many fought - on the battlefields, on the picket lines and in the daily round of love and duty - is no more.
> Are so many younger ones following their lead, because they know that this now lost world will never be theirs?

From observation, the majority of humanity prefers a fair degree of regularity for a reason: it usually lets us get on with life...

*Tie in with other services: In my experience with the 'homeless services' of [redacted] and [redacted], both seemed to do very little, until I was finally homeless and in temporary accommodation, then both closed their files. I have not [yet?] had interaction between the MHI system and public housing.

On two occasions at Centalink, young men exiting the prison system have found their payments and scripts not ready to access. On both occasions, frustrated by the bureaucracy they were confronted with, they became quite upset, both commenting: 'What do I have to do to get my regular medication? Rob someone and go back to jail?'

NDIS remains a minefield of inertia and bureaucracy. Being one of the first people signed up in the area in 2016, I still have not had a fulfilled plan. The current one is subject to a review that was filed in February, this year, for which I have not had any contact, even to an acknowledgement of receipt. A specialist attended an NDIS appointment with me. When he began coughing, he asked NDIS staff for some water. He was told that they don't supply that. People are supposed to bring their own. Such lack of common sense and courtesy cannot facilitate good relations between parties, or mental well-being.

Emergency services and military staff: stress that it might be good that they have depression/ptsd because it shows that they can still see the people they are dealing with as people, not just things/bits of flesh. The latter would be starting to border them being psychopaths, which would be a far more troublesome issue. More carefully vet potential military and emergency services staff? If not done already, should people in these fields –

from medics, police and prison workers, to the military and any associated administrative staff - be annually assessed, rather than just waiting for an ‘eruption’?

People in contact with, or employed by, the corrective services and justice system, etc. need training and awareness. eg: aphasia as a result of brain injury: how many people have been misperceived as stonewalling police during interviews, when they have the thoughts, but not the ability to express them? How many people employed in the Justice Services are themselves subject to mental health conditions and co-morbidities, which manifest themselves in their reactions to people and situations?

There is much I have not commented on, as some things are not within my experience. Others I will continue to work on, to clarify and expand, to ensure understanding.

*What should Victoria’s mental health system look like? Priorities?

Some priorities are:

1. sufficient public housing and proper supported accommodation, not more jail cells;

2. medical and support support systems, with:

    - properly trained staff;
    - adequate time allocated to see staff;
    - a system that is transparent and accountable and that has seamless tie-ins to other services, from the justice system, to court, housing, support services, etc;

3. for the First Australians, recognition of culture, country, history and the ties that bind, appropriate services and delivery, etc., so healing can take place;

4. an educated, supportive society that accepts MHI as a part of life, without negative discrimination.